

New Case Manager Position Approved

During the 2007 Legislative session a new Case Manager position was approved for the Arkansas Spinal Cord Commission.

Currently there are 14 Case Managers providing services to about 2,500 clients statewide. According to Client Services Administrator Patti Rogers, "This new position will bring much needed assistance to the Case Managers and more effective services to our clients. More than half of our current Case Managers have caseloads of over

185 clients and cover multiple counties."

The new Case Manager will be based in the Little Rock Case Management office and will cover Saline, Perry, Conway and parts of Pulaski County. This new position will provide a reduction in caseload size for at least eight Case Managers by reorganizing the coverage areas but will only effect 350 clients.

"Our goal is to provide the greatest amount of assistance as possible to

the Case Managers with the least amount of change for our clients," Ms. Rogers stated. The new Case Manager is anticipated to come on board in early November 2007 and caseload revisions will be made at that time. Clients who will be affected by the changes will be notified prior to the change.

The Commission is grateful to Governor Beebe and the 2007 legislature for this much needed position. With 15 Case Managers, ASCC will be better able to achieve our goal of assisting Arkansans with spinal cord disabilities in living as independently as they choose.

Sherry Cardell Honored

Sherry Cardell, a registered nurse (and an ASCC client), volunteers regularly at River City Ministry. Although she has experienced numerous health issues, Sherry has continued to work faithfully for the uninsured and homeless. Her devotion was recognized by the Arkansas Association of Charitable Clinics, who awarded her the honor of *Volunteer of the Year for 2006*. Chuck Morrison, Executive Director of AACC, presented Sherry with a plaque, and River City presented a celebratory cake. *Reprinted with permission from the River City Ministry News, Spring 2007.*



Annual Spina Bifida Christmas Party

This year's annual Christmas party will be held at the Baring Cross Baptist Church (next to Kohl's), 7541 Warden Road, in Sherwood, Arkansas on December 9th from 2:00 p.m. to 4:00 p.m.

Sponsored by the Spina Bifida Association of Arkansas (SBAAR), all children with spina bifida (under age 18) and other children in the household are invited to attend. See **Christmas Party** on page 7

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SPINAL COURIER

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With Thanks

Donations this quarter from:

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Betty Pridmore

In Memory of John Haskins

Nan Ellen and Jack East

Freda Hinerman

In Memory of Howard Wolford

David Huddleston

ASCC accepts tax-deductible donations. The generosity of the many individuals and families, who over the years have made memorial donations, is greatly appreciated. Contributions are used to assist our clients through purchases of equipment and educational resources.

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Dear Readers:

The first meeting of a new support group for clients, caregivers and family members was held in West Memphis at Crittenden Memorial Hospital on October 18th at 6 p.m.

ASCC and Crittenden Memorial Hospital are jointly sponsoring this group. For information on the next support group meeting, please contact me at **870-735-4725**.

Sharon McCoy
ASCC Case Manager

From the Director

Each month has its "cause." October is Spina Bifida Awareness month. It is also Breast Cancer Awareness month. This is the month of pink ribbons and the Komen Race for the Cure.

We all have our "causes." For me, breast cancer awareness is personal, from my own experience and for my friends who have joined our "club" of survivors. This summer, my friend Debbie died of breast cancer. She was 51 and had lived with spinal cord injury since age 15. She was smart, held a degree in public health, worked for Medicaid, had good insurance, and had no "family history." As "middle age" crept up, Debbie knew she should have a mammogram, but didn't want deal with the hassle—taking her clothes off was hard, finding an accessible center, making time; so, she put it off. By the time her "quad fingers" felt a tumor in a haphazard self-exam, it was big and had spread. She underwent chemo then radiation and fought a valiant battle for nearly five years. She didn't need to die; she had lots to give. In Arkansas, one in eight women will be diagnosed with breast cancer during her life and 400 will die each year.

Early detection is the answer. Mammography can find cancer cells that the naked eye can barely see. The American Cancer Society recommends that women over age 40 have a mammogram and clinical breast exam every year. Limited studies have shown that women with disabilities, especially older women and those with more severe disabilities, are less likely to receive mammograms.

So, what is your excuse? Virtually all insurance, including Medicaid and Medicare, pays for mammograms. If you don't have insurance, you can receive a free mammogram by contacting Arkansas Breast-care at 1-877-670-CARE. They will also help you find a wheelchair accessible screening site. Breast exam equipment has improved, training of technologists has improved; it isn't painless, but it isn't bad. If you are a woman over 40, get a mammogram! If you aren't, help me convince your wife, mother, sister, caregiver, partner or friend to get one. Her life may depend upon it!

Cheryl L. Vines

If you would like to make a contribution, please contact the Commission at **501-296-1788 / 1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission
1501 N. University, Suite 470
Little Rock, AR 72207

Spina Bifida Camp 2007



Morgan Love tries SCUBA diving.

This summer, we had 45 campers attend the Spina Bifida Camp June 24 to June 29.

Campers are divided into two tribes – the Caddo and Quapaw. As always, there was fierce competition between the two tribes. All week long these two teams competed in various activities to earn points.

These activities include swimming, fishing, accessible adventure/challenge ropes course, hand and/or foot driven catamarans, and adapted archery.



Ben Wells and Counselor Dustin Jandage play basketball.

On Friday morning, family members, friends and staff filled the Commons Building for the awards ceremony. Excitement grew as the campers piled into the auditorium. Each camper received an award. This year's winner of the Joe Morgan Super Camper award was Christina Cordon of Benton

This year's fishing tournament was sponsored by CenterPoint Entergy of Arkansas. Everyone who participated was presented with a trophy.

The winners of the two main categories were:

Most Fish Caught First Day: Ben Wells with 3

Most Fish Caught Second Day: Tia Ramsfield with 9

Biggest Weight Total First Day: Heaven Grigsby – 5 lbs 3 oz

Biggest Weight Total Second Day: Jaren Garmon – 2 lbs 10 oz

Biggest Fish Overall: Jake Geisler



Matthew Bell and Matthew Graham with Counselor Barnhouse go canoeing.

At last, the winning tribe was announced, and this year's winner was the **Quapaw** tribe.

Spina Bifida Camp is a collaborative program supported by the Arkansas Spinal Cord Commission, Camp Aldersgate and MedCamps of Arkansas.

If you missed Camp this year, and want to participate next year, be sure to look for details in our January 2008 newsletter, talk with your Case Manager, or contact Mary Jo Stanton at (501) 296-1788 or (800) 459-1517 or by e-mail at mjstanton@arspinalcord.org.



Christina Cordon going up the tree at the ropes course.



Ashlynn Redman and Counselor Sarah Stratton swimming.

Health Conditions in Arkansas Youth and Young Adults with Spina Bifida

By Andrea Hart*, Ph.D.

Dr. Mark Swanson (now with the Centers for Disease Control and Prevention in Atlanta) and I began working with Cheryl Vines and Tom Farley at the Arkansas Spinal Cord Commission (ASCC) in 2004 to study the development of secondary health conditions in Arkansans with spina bifida. The purpose of the study was to identify secondary conditions and other issues that prevent persons with spina bifida from living independently as they chose. ASCC Case Managers conducted interviews in the Fall of 2005 of child and adult clients, age 12 to 31, who were interviewed in a previous 1993 ASCC spina bifida study. The participants were asked questions about health, bowel and bladder management, weight, mobility, independence, living arrangements, social interactions, stress, depression, use of drugs and alcohol, sexuality, and quality of life.

As with any large study, the analysis has taken some time to complete. This article presents information collected from individuals with spina bifida, with the exception of data reported by their parents about independence. Future articles in the *Spinal Courier* will present information collected from the parents. Overall, we found that the research participants were eager to share their stories, and we are pleased to be able to share some of what we have learned.

Of the 180 individuals who participated in 1993 study, 153 were interviewed in 2005 resulting in a participation rate of 85 percent. Eighty-one were females, 72 males; 42 were children under age 18 and 122 were adults. Of those 153 individuals, 80 percent identified themselves as white, 16 percent black, 3 percent other, and 1 percent Native American. Lesion level was identi-

fied for 161 participants: 34 percent thoracic, 56 percent lumbar and 10 percent sacral.

Additionally, 154 parents were interviewed (137 mothers and 2 step-mothers, 9 fathers, and 6 other) for a participation rate of 85.6 percent. Of the 153 individuals with spina bifida, 11 did not have an equivalent parent interview. Of the 154 parents interviewed, 10 of those did not have a child interviewed. Therefore, we have a total sample of 164 families.

After the first interviews were complete, we contacted 28 of the participants for a second, more in-depth interview. We were particularly interested in exploring depression, weight management, social interactions, and level of independence.

WEIGHT: Thirty-three percent of children and 61 percent of adults rated themselves as overweight. Some individuals, who rated themselves as overweight, expressed their frustration about the difficulty of exercising due to mobility problems and lack of accessible facilities.

SOCIAL ISOLATION: 87 percent of adults and 100 percent of children said they were happy with the number of friends they had, but 56 percent of adults and 58 percent of children said they did not see their friends as much as they would like. Some of the reasons people gave for not seeing their friends often included no available transportation and not having a job that got them out in the community. Some teenagers mentioned that they have friends, but didn't really go out and do things with their friends. Another problem mentioned was that after high school graduation, friends got busy and didn't take the time to come visit. Some individuals talked

about how hard it was to find a romantic partner who could see past the wheelchair to the person.

DEPRESSION: We found that 32 percent of adults and 50 percent of children are at risk for major depression. During the in-depth interviews, we learned that feelings of depression are often related to not having a satisfying social life. We also learned that some individuals felt that they were not able to get treatment for depression because they couldn't talk to their families about seeking professional help or they didn't know where to get treatment. For more information about depression see the fact sheet on the National Institute of Mental Health website: <http://www.nimh.nih.gov/publicat/depression.cfm>

LEVEL OF INDEPENDENCE: When parents rated the level of independence of their adult children, many rated their child as not fully independent. For instance, 37 percent said their adult child was not fully independent in taking their medications. When individuals were asked about barriers to his or her own independence, many said that their parents didn't support them in becoming independent, and they wished they could get out on their own more.

Based on some of the results from this study, we are currently conducting a feasibility study to explore the best way to collaborate with several existing programs, including ASCC services and Arkansas Children's Hospital Spina Bifida Clinic, to establish a comprehensive program to assist youth in the difficult transition to adulthood.

We will continue to report about our research findings in future issues. See **Health Conditions** on page 5

Program Offers Hunt for Mobility-impaired Women

The Arkansas Game and Fish Commission (AGFC) along with the White River National Wildlife Refuge, are going to be offering women who have impaired mobility the opportunity to hunt. These women are fully capable of properly using a firearm, but have restricted ability to access land for a quality hunting experience.

Hunters are considered mobility-impaired if they have a permanent physical condition that severely restricts their mobility from either paralysis or amputation of lower extremities, according to AGFC Becoming an Outdoors-Woman (BOW) coordinator Phyllis Speer. "Basically, they must require assistance from a wheelchair, braces, crutches or other similar aids of mobility," she explained.

Health Conditions

Continued from page 4

sues of the *Spinal Courier* to keep you fully informed of our progress. We welcome any questions or comments. Feel free to contact me at: 501-682-9900, or hartandread@uams.edu. We want to take this opportunity to thank all the individuals and families who participated in the survey, and the ASCC Case Managers who collected the data.

The work *Secondary Conditions in Arkansas Children with Spina Bifida* was supported in full by the National Center on Birth Defects and Developmental Disabilities (NCBDDD) of the CDC through a cooperative agreement with Association of University Centers on Disabilities (AUCD). The opinions expressed are strictly those of the authors and do not necessarily reflect the opinions of the supporting organizations.

* Dr. Andrea Hart is Assistant Professor at the University of Arkansas for Medical Sciences in the Department of Pediatrics.

Hunters will be lodged at the Potlatch Education Center at Cook's Lake in eastern Arkansas. Food will be provided and those participating will be taken to, and picked up from their deer-hunting stand.

Each hunter will be required to have an assistant to help on the hunt as well as at the lodge. The hunters will be permitted to carry a modern firearm as described in AGFC regulations.

"It has been my privilege to coordinate the BOW program for the past 15 years. We hope that this deer hunt will reach a population of women who might not otherwise have the opportunity to participate in such an activity," Speer

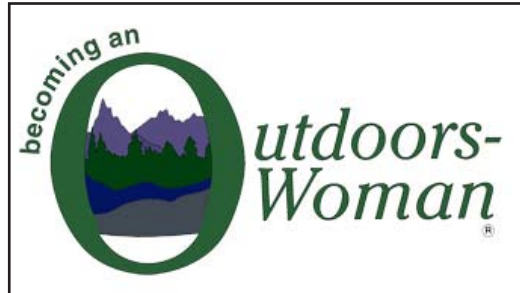
explained. "Our goal is to offer the women of Arkansas the opportunity to discover themselves and the great Arkansas outdoors," she added.

Each of the hunters will be allowed to harvest two deer; one legal buck and one doe. The hunt will be held

Nov. 16 at 1p.m. through Nov. 18 at noon. Applications must be submitted no later than Oct. 1. Qualifying applicants will be selected by a random drawing. Five applicants will be drawn for

this year's hunt. A second drawing will be held to form a waiting list in case of cancellations.

Those wishing to participate may contact Phyllis Speer for further information and applications at (870) 424-5750 or pspeer@agfc.state.ar.us.



Experimental Treatments and Clinical Trials: What You Should Know

Most people who sustain spinal cord injuries are told that they will never walk again, have feeling below injury level and will not see return of other functions. We have been told this for decades. In the last five years, that message has changed. New treatments and technologies are being developed and the science of spinal cord repair is moving ahead quickly. While there is still no promise of 'cure,' there is hope on the horizon.

In order to take these treatments from the laboratory to the clinic, they must be tried, first on animals and when deemed safe and effective, on humans. This process is called clinical trials and there are many spinal cord related clinical trials going on all over the world.

Scientists use many methods to recruit people to participate in clinical trials, on websites, by mail, through physicians and clinics and others. You may be contacted to participate in a clinical trial. Whether participation is right for you is a decision you and your family must make. In order to assist individuals with spinal cord disabilities and their families in making these decisions, ASCC has obtained a copy of a publication prepared by International Campaign for Cures of spinal cord injury Paralysis (ICCP).

This document is now available on our website. If you would like a paper copy, please call **800-459-1517** and ask for the clinical trials pamphlet.

Up Close and Personal: John Breen

This is the latest in a series of articles profiling the ASCC Case Managers.



John Breen is a caring and unassuming individual who is ASCC's Intake Coordinator. The Intake Coordinator completes initial assessments and coordinates services for all new referrals in Pulaski County. "John's dedication and empathy for his clients and their families knows no bounds. He often visits families at night in order to offer assistance," said Client Services Administrator, Patti Rogers. John's licensure as a Certified Social Worker and his experience with hospice patients and with children and teens in crisis has prepared him well. "I try my best to reassure folks, to provide the encouragement they need during this difficult time and show them that things are doable and the pieces will fit together eventually," John said.

In his spare time, John is very active in his Parish, serves as Knights of Columbus Youth Director and, with his wife, is very involved with Kaleidoscope Kids. John has also volunteered as a Big Brother to four little brothers for twenty years.

John is constantly on the go but you can get his attention by just mentioning sports. A dyed-in-the-wool Travelers, Cardinals and Packers fan, he always has time to talk about the latest game. You can usually find him at Dickey-Stephens Park cheering for the Travelers when they are in town.

PROFILE:

Date And Place Of Birth: October 31, 1958, in Memphis, TN.

Family Members: Wife, Janet, married 11-29-2003. We do not have any children but do have two dogs, Peanut and Sandy, who have some wonderful childlike qualities.

If I Did Not Live In Arkansas, I Would Want To Be: In St. Louis, Missouri—right across from Busch stadium.

I Absolutely Will Not Eat: Avocados or anchovies.

One Thing People Would Find Surprising About Me Is: I am a closet "Dead Head."

My Favorite Movie Is: *It's a Wonderful Life* but also *Casablanca*, *Pride of the Yankees*, *Knute Rockne All American*, and *Field of Dreams*. It's really hard to choose.

My Favorite Song Is: Just about anything played by the guitarist at our Parish.

I Am Most Comfortable With People Who: Are just regular folks.

My Favorite Pastimes Are: Anything sports related.

The Best Advice I Ever Received Was: Shortly before I married, a couple of men at church with long successful marriages took me aside and told me two phrases that would serve me well: "Yes dear" and "Honey I was wrong."

My Favorite Saying Is: "Aw, it's not too bad."

I Knew I Was Grown Up When: My wife expresses doubt that I will ever grow up!

One Word To Sum Me Up: Caring.

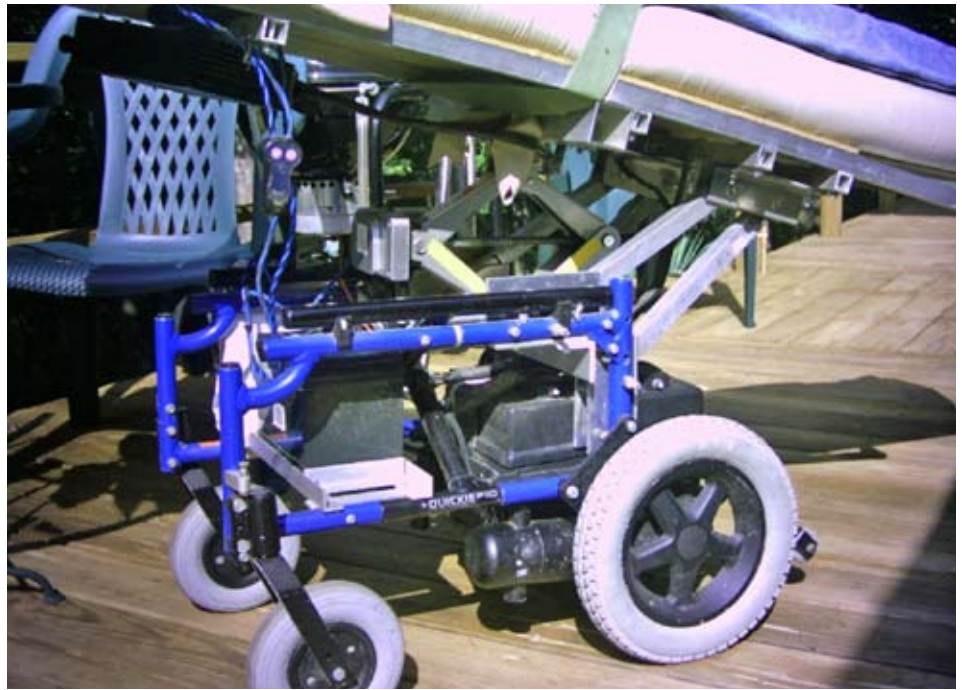
Christmas Party

Continued from page 1

Chef Gary will cook barbeque and serve up tasty side dishes for the group and SBAAR will furnish drinks. Families are asked to bring a favorite dessert to share. A mailed flyer will be sent out before the party so families can send in their kids' wish list. You must be present at the party in order to receive a gift.

This event is always a fun time for young and old alike. Santa has been known to stop by in order to hand out presents, so come join the fun!

For additional information please contact Vicki Rucker at **501-961-0820**.



David Paul's homemade prone cart. (See The Squeaky Wheel story on page 8.)

Arkansas Wheelchair Basketball Schedules

Fort Smith Shootin' Stars

The Fort Smith Shootin' Stars home tournament will be December 15, 2007 at the Butterfield Junior High School, 12th and Elm Street, Fort Smith, Arkansas. For more information contact Doug Moore at **479-474-0825**.

Little Rock Rollin Razorbacks

November 9-10, 2007	University of Alabama Invitational	Tuscaloosa, AL
November 16-18, 2007	Rockford Invitational (Rockford, Chicago and Charlottesville)	Rockford, IL
December 8-9, 2007	San Antonio Invitational	San Antonio, TX
December 15, 2007	Fort Smith Invitational	Fort Smith, AR
January 10-13, 2008	Pioneer Classic	Birmingham, AL
January 26-27, 2008	McKimmey Associates Realtors Invitational (Dallas, Rockford, Houston and San Antonio)	Sherwood, AR
February 9-10, 2008	Oklahoma University Invitational	Norman, OK
February 16-17, 2008	Dallas Invitational	Dallas, TX
February 23, 2008	Arkansas Valley Post-Season Tourney	Sherwood, AR
March 14-16, 2008	NWBA Regional Tournament	TBA
April 4-5, 2008	NWBA Division II National Championship	Lexington, KY

Home games played at Harmon Recreation Center, Sherwood, AR. For additional information contact Jared Johnson at **501-240-1529**.



The Squeaky Wheel

The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. “Things” can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you “should have done but didn’t.”

David Paul of Eureka Springs, Arkansas is a “do-it-yourself” kind-of-person. Here is his story:

After an abscess turned into a non-healing wound, I found a need to get some kind of prone cart to take the pressure off the affected area. I found one company online that made prone carts but the prices were ridiculously high. So, I made my own cart.

Later, I found out that a lot of people, especially amputees, live a large part of their life lying down. I’m here to tell you that six months in the same room can really test a person’s sanity. The first cart I

made got me out of my room but wasn’t very functional. So, working with my ASCC Case Manager, Maryanne Caldwell, I was able to get an older pediatric wheelchair and a few dollars for parts and convert it into a prone cart. The cart I built would have cost over \$10,000 if purchased from a vendor—mine cost a few hundred and time and effort. (*See photo on page 7.*)

My point in writing this is to say: “Don’t let life get you down. Don’t let obstacles stop you; see them as

a challenge. Where there’s a will, there’s a way.”

In closing, if there’s some gadget, chair, or other aide you can’t afford . . . make it! For those of you who can’t make what you need, perhaps I can help. When I get healed up in a few months, I’ll be back in the shop. Start thinking now of what could make your life easier and let’s see what we can do together down the road. You can contact me at davenbedky@peoplepc.com.

We invite you to send in your helpful hint—your bit of “grease.” Contact your ASCC Case Manager, write us at *Spinal Courier*, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at courier@arspinalcord.org and put “Squeaky Wheel” in the subject line.

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